
Nutrition Services for the Handicapped Child

MARIEL CALDWELL

SOME TYPE OF CHRONIC IMPAIRMENT affects 10 million children in the United States, according to the Select Panel for the Promotion of Child Health (1). Although it is difficult to find sound data on the numbers of children with chronically disabling or life-threatening disorders, estimates run as high as 3 million. In a Rand Corporation report, it is estimated that 2,883,000 children have sensory disorders (hearing, vision, and speech), 1,676,000 have other crippling conditions, and 50,000 are multiply handicapped. Also, 2 to 3 million children in the United States suffer from mental retardation (1).

Some of the major handicapping conditions affecting children today are fibrocystic disease, congenital heart disease, phenylketonuria, hemophilia, cerebral palsy, sensory

disorders, congenital anomalies (cleft palate, meningomyelocele), and mental retardation (2).

Importance of Nutrition

Adequate nutrition is essential for the growth and health of a handicapped child, just as it is for the growth and health of a normal child. A handicapped child has the same qualitative nutritional needs as do all children and may have even greater needs because of the handicap. In fact, nutrition may be the most important factor in the survival of some handicapped children. In others, it can play a role in preventing further delays in development or in reducing the debilitating effects of the handicapping condition, for example, of phenylketonuria and other metabolic errors.

Children with handicaps are vulnerable to the same stresses, including infectious disease, that place other children at nutritional risk, and they often have additional

problems with greater frequency than other children (3).

Studies have shown that developmentally delayed children are particularly susceptible to nutritional disorders, for example, low intake of nutrients, anemia, underweight, overweight, and short stature. Some nutritional disorders are linked to feeding problems such as difficulty in sucking, swallowing, chewing, food acceptance, and self-feeding (4).

Changes in Major Handicaps

The major handicapping conditions in children have changed over the past 50 years. Fifty years ago conditions such as poliomyelitis, with the resulting orthopedic deformities and other orthopedic consequences, were among the leading causes of handicapping. Since some of these problems could be resolved with surgery or other short-term intervention, nutrition was of minimal concern. Today, only a minority of children with crippling conditions require short-term intervention; nu-

Tearsheet requests to Ms. Mariel Caldwell, Regional Nutrition Consultant, Department of Health and Human Services, Region V, 300 South Wacker Dr., Chicago, Ill. 60606.

tritional care has been shown to be important in many of these conditions, and it often needs to be maintained for long periods (5).

At the time that orthopedic problems were of major concern, nutrition was a relatively new science, and much less was known about its relation to the normal growth, health, and development of children. Fifty years ago little research had been carried out on the special nutrition problems of the handicapped child, and health professionals had little training in the nutritional care of children with handicaps.

Developing Nutrition Services

In the early 1950s, the interest in mental retardation was reflected in the funding of child development clinics under Title V of the Social Security Act. In the clinics, health professionals skilled in caring for the mentally retarded provided comprehensive services for evaluating and treating children with this condition (6).

Increased national concern for the mentally retarded resulted in the establishment in the 1960s of the University Affiliated Centers for training health care professionals to evaluate and manage the treatment of developmentally disabled children. These centers employed nutrition personnel capable of providing appropriate nutrition services to the children referred to the centers. Nutrition assessment and treatment was, and is, an important part of this interdisciplinary training program.

The 1979 Amendments to the Social Security Act authorized new types of medical care projects that included intensive infant care. These projects provided for the regionalization of perinatal care and for making the services needed by the high-risk infant available

throughout the State. The importance of nutritional care for infants of low birth weight and infants with severe surgical problems became evident, and in 1978 three programs to train nutritionists in neonatal and perinatal nutrition were established. In 1970 the Minnesota State Crippled Children's Service became a pioneer in the development of nutrition services for children cared for by the program. A nutritionist was hired to provide assessment and counseling in the crippled children's clinics and to oversee the development of other hospital and community nutrition services needed by the population that was to be served. Today several States have full-time nutritionists in their crippled children's agencies, and others have arranged to have nutritionists assist in planning for or in providing direct services to the handicapped children.

In 1975, under the authority of the Title V grants to institutions of higher learning, project grant support was extended to selected regional pediatric pulmonary centers. The centers were to be models of excellence in the services, training, and research related to the respiratory diseases of infants and children. For a program to win approval, it was considered essential that the minimal core staff include nutritionists (7).

Further impetus was given to nutrition services for the handicapped child through the Supplemental Security Insurance/Disabled Children's (SSI-DC) program legislation, which covered many conditions requiring nutritional care as a major component of treatment. The accompanying regulations published in 1979 listed nutrition services as one of the services that was to be available to program-eligible children when such services were needed to assist in carrying out the child's individual service plan (8).

To provide guidance in implementing the SSI-DC regulations, a national conference was held in March 1980. The meeting focused on the nutritional needs of developmentally disabled children and their families. At this conference the nutritional problems of handicapped children were delineated, existing delivery systems for meeting their nutritional needs were identified, and the components of optimum delivery systems were proposed. Standards of professional practice were addressed, and recommendations were made for the training of the nutrition personnel who were engaged in providing the major components of nutritional care. The involvement of many disciplines and health care providers was identified as essential for comprehensive nutrition services, and recommendations were made for the development of inter- and intra-agency networks within States to meet the continuum of care needs of this handicapped population (9).

Following the conference, a committee was formed to prepare a programmatic guide for establishing and ensuring adequate nutrition services for the handicapped children served by crippled children's programs. In "Nutrition Services for Children With Handicaps, A Manual for State Title V Programs" (3), a system is outlined for assessing existing services and a protocol is presented for planning, implementing, monitoring, and evaluating nutrition services for the child with handicaps.

Recent Nutrition Research

In 1981, data became available from a collaborative study on the nutritional status of a group of developmentally disabled children. In this study, jointly carried out by four University Affiliated Centers (Ohio State University, Children's Hospital of Los Angeles, George-

town University, and the University of Washington), the nutritional status, physical development, and feeding characteristics of children who manifested delays of unknown etiology in their cognitive development were examined.

Dietary, clinical, biochemical, and social data from the study indicated a need for intervention in the areas of nutrition and feeding. Forty percent of the children in the study group were below the fifth percentile of the National Center for Health Statistics reference data for weight, height, or weight for height. Fifty-seven percent were delayed in their feeding-skill development, and feeding problems were associated with shorter stature and a lower weight-for-height ratio. When the subjects were classified by motor characteristics, the nonambulatory children were shorter, weighed less, and had less well-developed bones than children at the other motor extreme. Dietary and biochemical differences were found according to motor group, although there was evidence of nutritional risk in each group. Use of anticonvulsant medication was found to be a significant factor in nearly half of the biochemical variables (10).

Unmet Needs

Although great strides have been made over the past few decades in understanding the nutritional needs and problems of handicapped children, there is still much to learn about the specific nutritional needs and optimal care of children with many of the chronic and handicapping conditions that are observed today by the staffs of crippled children's services, University Affiliated Centers, and children's hospitals.

Training should be expanded for nutrition personnel and for other health care providers involved in

nutrition screening, assessment, and treatment of children with handicaps. Both long-term training, such as that offered by the University Affiliated Centers, which is intended to provide leadership in the field of mental retardation, and short-term training of health professionals to provide components of nutrition services in a variety of settings must increase. As more knowledge is obtained through research, continuing education for health personnel will continue to be needed.

Finally, administrators of programs serving the handicapped must become more aware of the importance of nutrition for that population. This awareness should result in more adequate planning of programs and better implementation of the nutrition services that are essential for the optimal development of many of the children served by these programs.

Conclusion

The many activities and developments underway show that there is broad interest and concern for the nutritional well-being of the handicapped child. Yet, although much has been done over the past few decades to improve the nutritional health of handicapped children, many tasks remain to be accomplished in the areas of nutrition research, education, and training and in the programming of nutrition services if these children are to reach their maximum potential and the highest possible quality of life.

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